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## BMJ Supportive & Palliative Care

### **BARRIERS AND FACILITATORS FOR CLINICIANS TO ENGAGE WITH ADVANCE CARE PLANNING IN HEART FAILURE: A SYSTEMATIC LITERATURE REVIEW AND QUALITATIVE EVIDENCE SYNTHESIS**

Journal:	<i>BMJ Supportive &amp; Palliative Care</i>
Manuscript ID	bmjspcare-2018-001747.R1
Article Type:	Review
Date Submitted by the Author:	23-Apr-2019
Complete List of Authors:	Schichtel, Markus; University of Cambridge, Department of Public Health and Primary Care Wee, Bee; Oxford University Hospitals NHS Trust, Palliative medicine; Ms MacArtney, John; University of Warwick Warwick Medical School, University of Warwick Collins, Sarah; Oxford Health NHS Foundation Trust
Keywords:	Heart failure, Advance care planning, Barriers, Facilitators, Systematic review, Narrative synthesis

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**Word count:** 3637 words

# BARRIERS AND FACILITATORS FOR CLINICIANS TO ENGAGE WITH ADVANCE CARE PLANNING IN HEART FAILURE: A SYSTEMATIC LITERATURE REVIEW AND QUALITATIVE EVIDENCE SYNTHESIS

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## ABSTRACT

**Background** Clinicians hesitate to engage with advance care planning (ACP) in heart failure. We aimed to identify the disease specific barriers and facilitators for clinicians to engage with ACP.

**Methods** We searched Medline, Embase, CINAHL, PubMed, Scopus, the British Nursing Index, the Cochrane Library, the EPOC register, ERIC, PsycINFO, the Science Citation Index, and the Grey Literature from inception to July 2018. We conducted the review according to ENTREQ guidelines. Two reviewers independently assessed original and empirical studies according to CASP criteria. The SURE framework and thematic analysis were used to identify barriers and facilitators.

**Results** Of 2308 articles screened, we reviewed the full text of 42 studies. 17 studies were included. The main barriers were lack of disease-specific knowledge about palliative care in heart failure, high emotional impact on clinicians when undertaking ACP, and lack of multidisciplinary collaboration between healthcare professionals in order to reach consensus on when ACP is indicated. The main facilitators were being competent to provide holistic care when using ACP in heart failure, a patient taking the initiative of having an ACP conversation, and having the resources to deliver ACP at a time and place appropriate for the patient.

**Conclusions.** Training healthcare professionals in the delivery of ACP in heart failure might be as important as enabling patients to start an ACP conversation. This two-fold approach may mitigate against the high emotional impact of ACP. Complex interventions are needed to support clinicians as well as patients to engage with ACP.

**Key words:** Heart failure, advance care planning, barriers, facilitators, clinicians, systematic literature review

**BACKGROUND**

To be better prepared in the event of a health crisis, conversations about care choices and future care planning in heart failure are widely recommended<sup>1-3</sup>. Advance care planning (ACP) is known to facilitate these conversations<sup>4, 5</sup> and may improve end of life (EOL) care outcomes<sup>6, 7</sup>. But a number of studies have shown that clinicians are hesitant to engage with ACP in clinical practice<sup>8, 9</sup>. Only the minority of eligible patients were given the opportunity of having these conversations<sup>10</sup>. As a result, patient care in heart failure is affected<sup>4</sup>. Only 37% of patients with end-stage heart failure were aware of a poor prognosis, merely 8% of patients and 44% of family members were told by clinicians that time was short, and 36% of these patients died alone<sup>11</sup>. The barriers and facilitators for *clinicians* to engage with ACP in heart failure have not been systematically evaluated.

Past reviews looked at barriers to ACP or conversations in heart failure, but no review had rigorously assessed the qualitative evidence base for barriers and facilitators to engage *clinicians* with ACP in heart failure. Lund et al's<sup>12</sup> systematic review investigated the barriers and facilitators to the implementation of ACP focussing on their workability and integration in clinical practice. However, their review did not concentrate on heart failure and addressed only to some extent the barriers facing clinicians. The review by Barclay et al.<sup>13</sup> investigated the literature concerning conversations between professionals and patients suffering from heart failure but did not focus on barriers to ACP. Momen's et al.<sup>14</sup> narrative synthesis reviewed the extent to which there was evidence that conversations with heart failure patients occurred in practice and built on findings from Barclay's work. Similarly, her narrative did not focus on barriers to the implementation of ACP. Slort et al.<sup>15</sup> identified barriers and facilitators for the general practitioner – patient communication in palliative care. While some of their findings were relevant to this study, the authors did not focus on heart failure or on barriers to the implementation of ACP by clinicians. De Vleminck et al.<sup>16</sup> did explore perceived factors hindering or helping GPs in engaging with ACP but a focus on the disease-specific barriers to heart failure was missing. A qualitative synthesis of the evidence by Smeets et al.<sup>17</sup> sought to identify barriers and facilitators for optimal care in heart failure from a GP's perspective. But the study did only concentrate on the clinical management aspects of heart failure rather than on what might improve clinicians' behaviour to initiate ACP. Consequently, a focus on ACP was lacking. Hence, the gap in the evidence was an identification of barriers and facilitators to the engagement of clinicians with ACP in heart failure.

**AIM AND OBJECTIVES**

The aim of this study was to conduct an exploratory systematic review of qualitative studies investigating the barriers and facilitators to the implementation of ACP by clinicians in heart failure.

The objectives were as follows:

- To identify the barriers and facilitators to the implementation of ACP by healthcare professionals in heart failure
- To synthesise the evidence on recommendations on how to engage clinicians with ACP in heart failure

## METHODS

We conducted the review according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement<sup>18</sup>. This included, but was not limited to, defining the research aims and objectives, developing a review protocol, conducting data base searches, extracting data based on in- and exclusion criteria, assessing the methodological quality of studies and synthesising the evidence<sup>19, 20</sup>.

### Inclusion/ Exclusion Criteria

#### Types of studies

We included studies that used qualitative study designs and reported original and empirical study data. Qualitative methods for data collection were focus groups, interviews, observational studies, surveys and document analysis. Studies had to address barriers and facilitators for healthcare professionals to engage with ACP in heart failure. Barriers and facilitators were defined as predisposing factors described by clinicians that either impede or promote their engagement with ACP<sup>21</sup>. Studies describing other terminal illnesses but not heart failure were excluded from the primary analysis. Studies that described ACP for people with life-limiting illnesses that involved heart failure were included. Editorials and narrative reviews were excluded unless they presented original study findings.

#### Types of participants

Participants included were all healthcare professionals like GPs, primary care nurses, palliative care consultants and nurses, cardiologists, heart failure specialist nurses, providing EOL care for patients suffering from heart failure. Studies that solely focussed on patients without any reference to healthcare providers were excluded from the review.

#### Types of interventions

ACP was defined as a *process* of formal decision-making that aimed at helping patients make decisions about their future care<sup>4</sup>. As such ACP could provide an opportunity for clinicians to clarify a patient's care preferences in anticipation of future loss of mental capacity. This could involve future treatment choices or resuscitation options. In this way, ACP was meant to reduce uncertainty about a course of action should the clinical status of a patient deteriorate and capacity is lost<sup>22</sup>.

Types of outcome and healthcare setting

We included studies that primarily described the perceptions and experiences of healthcare professionals on barriers and facilitators to their engagement with ACP in clinical practice. The healthcare setting could be primary care, nursing homes, secondary care, hospital or hospices.

Search strategy and data sources

Studies were retrieved through systematic searches of electronic data bases, screening reference lists and contacting authors. Together with a specialist health science librarian (NR), we searched the following data sources: Medline, Embase, CINAHL, PubMed, Scopus, the British Nursing Index, the Cochrane Library, the EPOC register, ERIC, PsycINFO, Science Citation Index, and the Grey Literature. We searched data bases from their inception until July 2018. An example of a MEDLINE search strategy is provided in **Appendix 1**. Additionally; we searched the reference lists of five reviews<sup>12, 13, 15-17</sup> and all potential relevant cross references and records to identify any other studies. Where required, we contacted the study authors or experts in the field for further information.

Data analysis

We elected to use a thematic synthesis approach which drew on the methods from thematic analysis of primary sources<sup>23</sup> and managed these findings with the SURE framework<sup>24</sup>. The SURE framework (**Appendix 2**) had been validated across a number of healthcare sectors as a systematic yet flexible approach to analysing and categorising qualitative data to inform healthcare policy<sup>25-27</sup>.

Selection of studies

Two reviewers (SC, MS) independently assessed titles and abstracts of identified studies against inclusion criteria. Full text papers were retrieved if the content was potentially relevant to one or both authors. Two authors (MS, SC) evaluated whether these studies should be included in the review. Differences between reviewers were resolved by discussion. A list of excluded papers with reasons for their exclusion is given in **Appendix 3**.

Data extraction and management

Initially, we extracted the background information on each included study (study objectives, study design and methods, participants) and summarized these in tables. Following that, we designed a data extraction sheet that was informed by components of the SURE framework. Components of the data extraction focussed on barriers and facilitators to implementing ACP by clinicians in healthcare systems. We extracted data from included studies and mapped them on to the relevant categories of the SURE framework.



## Quality assessment

Two authors (MS, SC) independently assessed the quality of included studies by using the Critical Appraisal Skills Programme (CASP) quality assessment tool<sup>28</sup>. We used its seven main quality criteria for assessment (**Appendix 4**). Each criterion was assessed with 'yes' or 'no.' If the study did not present adequate information, the rating was 'no.' This resulted in a total quality score ranging from 0 to 7 after applying equal weights. Individual studies were categorised as high quality (ratings from 6 to 7), medium quality (ratings from 4 to 5), and low quality (scores equal or lower than 3). We excluded studies of poor quality and resolved differences by discussion.

## Data synthesis and analysis

Findings were corroborated narratively using a thematic synthesis approach which drew on the methods from thematic analysis of primary sources, extending them to systematic reviews<sup>29</sup>. Thematic synthesis was one of a number of methods suggested by the Cochrane Qualitative Review Methods Group<sup>30</sup> where evidence was likely to be largely descriptive as opposed to highly theorised or conceptual. After reading the text of each study, we developed 'descriptive themes.' We (MS, BW, JM) discussed the set of descriptive themes which informed the categories of the SURE framework as a pragmatic approach that was designed to inform healthcare policy.

## RESULTS

The literature search identified 2308 potentially eligible studies, of these, 17 papers were included in the final qualitative synthesis (**Figure 1**. PRISMA Flow Diagram). Most studies (n=11) were conducted in the UK. Two studies were undertaken in Australia<sup>31, 32</sup>, one in Canada<sup>33</sup>, one in Sweden<sup>34</sup>, the USA<sup>35</sup> and Belgium<sup>16</sup>. The majority of studies (n=13) included clinicians from primary care. A summary of included study characteristics is given in **Table 1**.

**Figure 1. PRISMA flow diagram**



Study ID	Country	Relevant study objectives:	Study Design	Participants	CASP Quality assessment (Score)
Barnes (2006) <sup>36</sup>	UK	To explore attitudes of primary care professionals and older people toward communication of diagnosis, prognosis and symptoms in CHF	Focus groups with HCPs and interviews with patients	39 GPs, 37 nurses, 2 health visitors, 1 nursing home manager, 41 patients with CHF	High (6)
Bloomer (2013) <sup>31</sup>	Australia	To explore and identify the preparedness and ability of nurses to provide end of life care through the patient's dying phase and their families	Focus groups study with clinical nursing and management staff	12 nurses from an intensive care unit looking after cardiac and surgical patients	High (6)
Boyd (2004) <sup>37</sup>	UK	To identify some barriers and facilitators for clinicians to engage in ACP with patients in their last phase of life.	Interviews and focus groups with patients, carers and clinicians	16 clinicians from primary and secondary care, social and palliative care specialists	High (7)
Brooks (2017) <sup>32</sup>	Australia	To explore the experiences of physicians and nurses on barriers and enablers to providing EOL care	Focus group study	11 physicians and 17 nurses at an intensive care unit	High (6)
Close (2013) <sup>38</sup>	UK	To examine the experience of heart failure diagnosis of HCPs, nursing home staff and residents	Qualitative interviews	5 GPs, 3 HF nurses, 17 nursing home residents	High (6)
De Vleminck (2014) <sup>16</sup>	Belgium	To identify barriers from a GPs perspective to initiating ACP and to gain insight into any differences in barriers between cancer, CHF and dementia	Five focus groups with General Practitioners	36 General Practitioners looking after terminally ill patients	High (6)
Denvir (2014) <sup>39</sup>	UK	To explore the optimal content and design of a trial on EOL intervention for advanced heart disease	Community and hospital based focus groups and interviews	11 Primary and secondary care healthcare professionals	High (6)
Fuat (2003) <sup>40</sup>	UK	To ascertain the beliefs and decision-making practices of GPs in the heart failure	Focus group study	30 GPs	Medium (5)
Glogowska (2015) <sup>41</sup>	UK	To explore perceptions and experiences of HCPs caring for patients suffering from HF	Qualitative interview study	24 HCPs including GPs, cardiologists, geriatricians, HF specialist nurses	High (7)
Hancock (2014) <sup>42</sup>	UK	To explore changes in HCPs views about the diagnosis and management of HF	Focus groups and a national survey	56 focus group participants (39 GPs, 4 cardiologists, 6 general physician, 7 HF nurses); 514 survey responses	High (7)
Hanratty (2002) <sup>43</sup>	UK	To identify doctors' perceptions of the need for palliative care for heart failure and barriers to change	Focus groups study	34 GPs, cardiologists, geriatricians, medical and palliative care doctors	High (6)

<b>Hayes (2015)<sup>33</sup></b>	Canada	To identify the potential challenges and opportunities to improve care for CHF in the community	Clinician interview series	28 HCPs including 5 GPs, 8 cardiologists, 8 nurses, and 4 pharmacists, 3 admin staff	High (7)
<b>Hjelmfors (2014)<sup>34</sup></b>	Sweden	To describe nurses' perspective on discussing EOL issues and prognosis with CHF patients	National survey	111 heart failure nurses	High (6)
<b>Murray (2015)<sup>44</sup></b>	UK	To document the barriers and facilitators to palliative care in the community	European survey	Primary care HCPs from 20 European nations	High (7)
<b>Ostertag (2008)<sup>35</sup></b>	USA	To identify concerns about EOLC amongst HCPs and members of the community	Interview and focus group study	14 primary care physicians, 19 hospice staff, 18 nursing home staff, 19 carers	Medium (5)
<b>Selman (2007)<sup>45</sup></b>	UK	To investigate communication between staff, patients and carers on EOL issues for patients suffering from heart failure	Semi-structured qualitative interviews	20 patients with CHF, 11 carers, 6 palliative care clinicians and 6 cardiology clinicians	High (7)
<b>Seymour (2010)<sup>46</sup></b>	UK	To identify factors surrounding community nurses' implementation of ACP and nurses educational needs	Six focus group discussions and three workshops	23 community nurses looking after patients affected by a terminal illness	High (7)
<b>Abbreviations</b>	<b>CHF:</b> congestive heart failure; <b>EOL:</b> end of life; <b>EOLC:</b> end of life care; <b>GP:</b> General Practitioner; <b>HCP:</b> healthcare professional; <b>HF:</b> heart failure;				

**Table 1. Characteristics of included studies**

Methodological quality of studies

Of the 17 papers, we rated 15 as high quality (CASP score 6-7) and two as medium quality (CASP score 4-5)<sup>35, 40</sup>. One study was excluded due to low quality<sup>47</sup>. The CASP quality ratings of the included studies are summarized in **Table 2**.

Study ID	CASP question addressed: Yes = +                      No = o						
	1	2	3	4	5	6	7
Barnes (2006)	+	+	+	+	+	o	+
Bloomer (2013)	+	+	+	+	+	+	o
Boyd (2004)	+	+	+	+	+	+	+
Brooks (2017)	+	+	+	+	+	o	+
Close (2013)	+	+	+	+	+	o	+
De Vleminck (2014)	+	+	+	+	+	+	o
Denvir (2014)	+	+	+	+	+	o	+
Fuat (2003)	+	+	+	+	o	+	o
Glogowska (2015)	+	+	+	+	+	+	+
Hancock (2014)	+	+	+	+	+	+	+
Hanratty (2002)	+	+	+	+	+	+	o
Hayes (2015)	+	+	+	+	+	+	+
Hjelmfors (2014)	+	+	+	+	o	+	+
Murray (2015)	+	+	+	+	+	+	+
Ostertag (2008)	+	+	+	+	o	o	+
Selman (2007)	+	+	+	+	+	+	+
Seymour (2010)	+	+	+	+	+	o	+

Table 2. CASP quality assessment

Barriers and facilitators

We summarised the factors reported as barriers and facilitators for the engagement of clinicians with ACP in heart failure using the SURE framework (**Table 3**). All barriers and facilitators at a clinician level were categorised under a) knowledge and skills, b) attitudes regarding ACP’s acceptability, appropriateness and credibility, and c) motivation to engage with ACP.

Factors affecting implementation of ACP	Barriers	Facilitators
Knowledge and skills	<ul style="list-style-type: none"> <li>lack of knowledge about palliative care in heart failure (e.g. the complexity of drugs, ICDs, CRTs)<sup>16, 31, 36, 37, 40, 42, 44, 45</sup></li> <li>lack of knowledge about the legal differences between ACP and ADRTs<sup>16, 35, 44, 46</sup></li> <li>uncertainty about HF prognosis<sup>34, 39, 42, 43, 45</sup></li> <li>lack of EOL communication and negotiations skills<sup>16, 34, 45</sup></li> <li>lack of time to start and complete an ACP conversation<sup>16, 31, 34, 39, 41</sup></li> <li>lack of collaboration with other HCPs about the patient<sup>32, 40</sup></li> <li>not remembering to initiate ACP in the rush of everyday clinical practice<sup>16, 31</sup></li> <li>using euphemisms when talking about heart failure and the prognosis<sup>32, 42, 46</sup></li> </ul>	<ul style="list-style-type: none"> <li>being competent about palliative care in heart failure<sup>36, 37, 42, 45</sup></li> <li>knowing what ACP is and what it is not<sup>16, 44, 46</sup></li> <li>knowing the legal differences between ACP, ADRTs or living wills<sup>16, 35, 46</sup></li> <li>creating more time by having ACP conversations in the context of a home visit or by booking double appointments<sup>32, 34, 42, 46</sup></li> <li>being able to engage patients in shared decision-making and ACP<sup>32, 37, 40, 42</sup></li> <li>consultation with other HCPs about next steps in EOLC for the patient<sup>35, 40</sup></li> <li>having some sort of reminder to indicate the need to do ACP for a patient<sup>16, 46</sup></li> <li>being able to clarify what a patient wants to know and what a patient does not want to know<sup>36, 45</sup></li> </ul>
Attitudes regarding ACP's acceptability, appropriateness and credibility	<ul style="list-style-type: none"> <li>uncertainty about timing of ACP<sup>16, 34, 45, 46</sup></li> <li>emotional difficulties of having an ACP conversation<sup>16, 42, 45</sup></li> <li>ACP perceived as admitting defeat or as a failure to a medical treatment prerogative<sup>32, 39</sup></li> <li>believing that cardiologists or heart failure specialist nurses are better suited than GPs because of their expertise<sup>16, 38, 41-43</sup></li> <li>believing that GPs are better suited than cardiologists because they have a long-standing relationship with the patient<sup>16, 41</sup></li> <li>waiting for the patient to start a conversation about EOL issues<sup>16, 36, 37</sup></li> <li>concerns about the impact of ACP on the patient and the family<sup>36, 41</sup></li> </ul>	<ul style="list-style-type: none"> <li>knowing the patient and family to identify the appropriate moment to have an EOL conversation<sup>16, 31</sup></li> <li>knowing a patient's care preferences and values<sup>34, 36</sup></li> <li>being able to provide a range of treatment options appropriate to the patient's phase of illness<sup>16, 45</sup></li> <li>sharing information between primary- and secondary healthcare teams to identify who is the appropriate HCP to have an ACP conversation and when<sup>16, 32, 33, 37-41, 43</sup></li> <li>empowering patients to initiate EOL conversations with their healthcare provider<sup>16, 36, 41</sup></li> </ul>
Motivation to engage with ACP	<ul style="list-style-type: none"> <li>not wanting to alarm patients<sup>16, 36, 46</sup></li> <li>not wanting to destroy hope when initiating ACP conversations<sup>34, 39, 46</sup></li> <li>being afraid of talking about death and dying<sup>32, 36, 41, 46</sup></li> <li>fear of damaging the clinician - patient relationship<sup>46</sup></li> <li>fear of suggesting to patients that HCPs give up<sup>38</sup> on them when introducing ACP<sup>39</sup></li> <li>lack of human resources discourages HCPs to undertake ACP<sup>31, 42, 46</sup></li> </ul>	<ul style="list-style-type: none"> <li>being able to provide holistic end of life care<sup>33, 36, 37, 39</sup></li> <li>knowing that patients want their HCPs to be honest with them<sup>32, 36, 41</sup></li> <li>being able to improve the quality of life for patients and their carers when doing ACP<sup>38, 46</sup></li> <li>an opportunity to be open and transparent with patients and give them a chance to prepare for the end of life<sup>32, 46</sup></li> <li>increased resources in terms of time and staff to undertake ACP and provide 'good' EOLC<sup>31, 42</sup></li> </ul>
<b>Abbreviations:</b> ACP: advance care planning; ADRTs: advance decisions to refuse treatment; CRT: Cardiac Resynchronization Therapy; EOL: end of life; EOLC: end of life care; HCPs: healthcare professionals; HF: heart failure; ICD: implantable cardioverter defibrillator;		

Table 3. Barriers and facilitators for clinicians to engage with ACP

**Barriers to clinicians**

We identified the following key barriers to the engagement of clinicians with ACP in heart failure:

- **Knowledge and skills**

One common reported barrier for clinicians to engage with ACP in heart failure was a lack of heart failure disease-specific knowledge<sup>36, 40, 44, 45</sup> which mainly affected GPs<sup>42</sup>, primary care nurses or palliative care staff<sup>33</sup>. This related predominantly to the complexity of available drugs or the use of implantable cardioverter defibrillator (ICDs) and cardiac resynchronization therapy (CRT)<sup>37, 33, 42</sup>. Many times, this disease-specific barrier was aggravated by uncertainty about the prognosis of the illness which prevented ACP from taking place<sup>34, 36</sup>.

Furthermore, healthcare professionals described a lack of knowledge about ACP in general<sup>33, 46</sup>, what ACP should contain or what the legal differences were between ACP and advance decisions to refuse treatment (ADRTs)<sup>35, 46</sup>. This in turn made communication about ACP very challenging for clinicians. A number of studies described a lack of communication- and negotiation skills in EOLC as a barrier to the implementation of ACP<sup>32, 46, 48</sup>. Euphemisms were seen as a way to avoid talking about heart failure as a diagnosis<sup>42</sup> as well as the terminal nature of the disease<sup>16, 36</sup>. However, the use of euphemisms was generally not endorsed by healthcare staff<sup>32</sup>.

- **Attitudes regarding ACP’s acceptability, appropriateness and credibility**

One attitude emerging as a barrier in implementing ACP by clinicians in heart failure was the perception that in doing so a healthcare professional would admit defeat and treatment failure<sup>34</sup>. This was associated with a considerable negative, emotional impact<sup>45</sup>. Similarly, some studies reported that clinicians saw engaging with ACP as a setback to any curative treatment effort<sup>42, 49</sup>. This attitude applied more to cardiologists than to primary or palliative care staff<sup>40</sup>. Another barrier for not undertaking ACP was a lack of collaboration between healthcare professionals. Cardiologists believed that a GP was better suited to have an ACP conversation due to a GP’s long-standing relationship with the patient<sup>43</sup>. Conversely, some GPs thought that the cardiologist was the professional with the content expertise and therefore should start ACP<sup>38</sup>. There was a general lack of communication between the medical disciplines on the issue<sup>37, 42</sup>. Others reported that clinicians waited for the patient to initiate these discussions so that they were sure it was the appropriate time to engage with ACP<sup>46</sup>. Underlying that lack of initiative were also fears and concerns of not wanting to upset the patient or the family<sup>34, 38</sup>.

- **Motivation to engage with ACP**

Not wanting to cause alarm to patients or carers was a key motivational barrier for clinicians not to engage with ACP<sup>34</sup>. They feared that in delivering ACP, healthcare professionals would destroy hope<sup>37</sup>. Another study reported that their own fear of talking about death and dying was another reason for not speaking to patients about the last phase of life<sup>33</sup>. Some clinicians feared that starting an ACP discussion would

indicate to a patient that they would give up on them and consequently damage their doctor-patient relationship<sup>46, 49</sup>. Another major factor that discouraged clinicians from engaging with ACP was a lack of resources<sup>37, 38, 40, 44, 46</sup>, mainly time, qualified staff<sup>38</sup> and the right opportunity to address such a sensitive topic<sup>39</sup>. Additional barriers to motivation of healthcare professionals to carry out ACP were the competing demands of their clinical role. Workloads and stress often prevented some clinicians from undertaking ACP in heart failure<sup>37, 42</sup>.

## Facilitators for clinicians

Studies reported a number of significant facilitators to engage clinicians with ACP in heart failure:

- **Knowledge and skills**

Being competent in managing the complexities of palliative care in heart failure was a key factor for clinicians to engage with ACP<sup>36, 46</sup>. Other studies reported that a robust knowledge of drug regimens and the issues surrounding the use of ICDs and CRTs boosted a clinician's confidence to start the ACP process<sup>41, 45</sup>. Healthcare professionals were also more likely to deliver ACP if they had a good understanding about what were the essential criteria of ACP<sup>36, 44, 46</sup>. This was especially relevant when understanding the legal differences between ACP, ADRTs or living wills<sup>46</sup>.

Essential skills for implementing ACP were reported as being able to identify the level of a patient's need for information<sup>36</sup>, clarifying a patient's care preferences and values<sup>31</sup> or being able to engage a patient in a shared decision-making process on all available treatment options<sup>32, 37</sup>. Study participants described that obtaining or maintaining these skills always involved some form of training<sup>37, 43, 48</sup>. These skills were also relevant when introducing the topic of ACP to a patient<sup>36, 44, 46</sup>. Starting the ACP process could happen in the context of an outpatient appointment, a routine medication review or after a hospital admission when the patient was in a stable medical condition<sup>42</sup>.

- **Attitudes regarding ACP's acceptability, appropriateness and credibility**

Studies reported a number of attitudes that appeared to promote clinicians' engagement with ACP. Some thought that ACP was easier to initiate when they knew the patient and family well<sup>32</sup>. The context of a long-term doctor - patient relationship was conducive for a clinician to identify the right place and time to have an EOL conversation<sup>34, 41</sup>. Similarly, the timing for an ACP conversation was seen as appropriate when a patient initiated the conversation<sup>41</sup>. Some clinicians described a sense of relief when this occurred<sup>46</sup>. Additionally, starting the ACP process was perceived as being easier when primary- and secondary healthcare teams collaborated well and had reached consensus on a patient<sup>33, 37, 41, 44</sup>.

- **Motivation to engage with ACP**

One of the key motivations for clinicians to deliver ACP was being able to provide good or holistic<sup>37</sup> EOL care. Some clinicians thought that ACP was able to improve the quality of life for patients and their carers<sup>35, 37</sup>. ACP gave clinicians the stimulus to be open and transparent<sup>35</sup> and created an opportunity to prepare patients for their

last phase of their life<sup>43</sup>. A few studies described that an increase in human resources including more staff time and finances were additional motivational factors to deliver ACP<sup>37, 42, 44</sup>. To resolve the lack of time, some healthcare professionals started ACP in the context of a home visit<sup>37</sup> or by booking a double clinic appointment. Others arranged follow-up visits after the initial conversation to address any unresolved issues<sup>38, 46</sup>.

**DISCUSSION**

This review synthesised the qualitative evidence from 17 primary studies on barriers and facilitators to the engagement of clinicians with ACP in heart failure. Systematic review methods were based on recommended standards to enhance transparency and reporting for qualitative evidence<sup>19</sup>.

Significant themes for barriers to the engagement of clinicians with ACP in heart failure were:

- Lack of disease-specific knowledge about palliative care in heart failure
- Lack of skills in communicating ACP with a patient suffering from heart failure
- Lack of collaboration between healthcare professionals in order to reach consensus on when ACP is indicated
- The high emotional impact on the healthcare professional when undertaking ACP

Important themes for facilitators to help clinicians engage with ACP in heart failure were:

- Being competent in the use of ACP and the clinical management of end stage heart failure
- Being able to provide holistic EOL care when using ACP
- Having a trusting and long-term relationship with the patient and carers
- A patient initiating an ACP conversation
- Being able to deliver ACP at a time and place appropriate for the patient

**Comparison with existing literature**

Several of our findings on barriers and facilitators concurred with those from other reviews: the complexity and inherent uncertainty of some aspects of end-stage heart failure management<sup>17</sup>, skills in initiating ACP and communicating EOL issues<sup>13, 49</sup> or having sufficient resources<sup>12</sup> and a functioning network of collaborations between medical specialities<sup>17</sup> applied to our results as well. Educating and training clinicians in the delivery of ACP should help them become more skilled with the process of initiating these conversations. Being able to conduct these discussions was seen as important, since there were suggestions that supportive or palliative care for heart failure patients should be made available at all stages of the disease trajectory<sup>50</sup>. Having these conversations as a normal part of heart failure management was balanced by the precaution to adjust the dialogue to a patient’s need for information in order to avoid a loss of hope or an increase in anxiety<sup>14</sup>. This applied particularly to patients who did not want to talk about EOL issues or engage with ACP<sup>51</sup>. Again,



this precaution had to be considered in the context that a number of clinicians avoided disclosing the diagnosis of heart failure all together or evaded answering any questions about the prognosis of the illness<sup>52</sup>. But the majority of patients preferred open and honest information about their condition while maintaining a sense of hope<sup>51</sup>. So, the training of clinicians in communicating ACP sensitively seemed even more important.

## Strengths and limitations

This was the first qualitative synthesis specifically addressing barriers and facilitators for engaging clinicians with ACP in heart failure. Several of our findings concurred with other reviews. However, the global transferability of our qualitative results may be limited since the majority of included studies were based in the UK. Some studies included other life-limiting illnesses like cancer or COPD in addition to patients suffering from heart failure. Some studies included other life-limiting illnesses like cancer or COPD in addition to patients suffering from heart failure. Consequently, our findings may have been affected by barriers and facilitators to the implementation of ACP that exist in other end-of-life conditions and not just heart failure.

The SURE framework proved to be helpful in facilitating an understanding of the barriers and facilitators to the implementation of ACP in the published literature. This approach facilitated the synthesise of findings from the thematic analysis in a systematic way according to healthcare professionals' knowledge and skills, their attitudes regarding ACP's acceptability, appropriateness and credibility and their motivation to engage with ACP. Once we achieved consensus on the barriers and facilitators in included papers, mapping these to the SURE structure was efficient and straight forward.

Conversely, using the SURE framework largely centred the analysis of thematic findings on barriers and facilitators to the implementation of ACP by clinicians. This approach may have limited the diversity of qualitative data and narrowed the complexity of the phenomenon under investigation to factors affecting the implementation of the intervention by clinicians. Consequently, there may have been a risk that other themes outside the scope of SURE were not sufficiently considered like the wider political or cultural context of ACP.

A novel finding from this review suggests that patients may hold the key in engaging clinicians with ACP<sup>41</sup>. Their initiative in starting an ACP conversation might have the potential to mitigate against the high emotional impact on healthcare professionals<sup>33, 38</sup>. The literature suggests that, for example, question prompt lists (QPLs) have the potential to empower patients to initiate EOL conversations with their healthcare provider<sup>53</sup>. If a patient initiates the discussion about ACP in heart failure, clinicians may feel less reticent about raising the topic by responding to a patient's question. A number of studies report a small but significant increase in questions by patients about diagnosis, prognosis and treatment when a QPL had been used<sup>53, 54</sup>. Most of these studies investigated the effect of QPLs in a cancer setting. Further research for the effect of QPLs on patients suffering from heart failure is still outstanding since these studies investigated the effect of QPLs in a cancer setting.

**Conclusions and recommendations**

This review has shown that clinicians often lack disease-specific knowledge about the clinical management of advanced heart failure and the confidence to engage with EOL issues and ACP. Available evidence suggests that training clinicians should include skills to identify the level of a patient’s need for information, clarifying a patient’s care preferences and values and being able to engage a patient in a conversation on all available treatment options. There are a number of suggested methods to achieve these skills which may include interactive educational meetings involving role play preferably facilitated by local opinion leaders and experts in the field of heart failure to enhance clinicians’ engagement.

Based on current findings, training clinicians in the delivery of ACP in heart failure might be equally important to assisting patients to start an ACP conversation. This two-fold approach may mitigate against the high emotional impact of ACP on healthcare professionals. Complex interventions are needed to support both, clinicians as well as patients, to engage with ACP in heart failure.

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## DECLARATIONS

### Contributorship

The list of authors including the main author, Markus Schichtel (MS), and the co-authors, Bee Wee (BW), John I. MacArtney (JIM), and Sarah Collins (SC) represents all those who can legitimately claim authorship by making a substantial contribution. MS had the idea for the review, wrote the protocol, extracted, evaluated and analysed the data, wrote, critically revised and submitted the entire manuscript. BW critically supervised the conduct of the review and revised the entire manuscript. JIM critically revised the study protocol, the narrative synthesis as well as the SURE analysis of barriers and facilitators. SC independently screened papers, extracted data and evaluated the study quality according to the CASP assessment tool. All co-authors approved the version to be published.

### Funding

This research and authors received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### Competing interests

The author(s) declare no potential conflicts of interest with respect to the research, authorship, and /or publication of this article.

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### Ethics statement

This systematic review and narrative synthesis did not require ethics approval.

### Acknowledgements

We thank Nia Roberts, health science librarian, Bodleian Library, University of Oxford, for running the literature data base searches.

**BARRIERS AND FACILITATORS FOR CLINICIANS TO  
ENGAGE WITH ADVANCE CARE PLANNING IN HEART  
FAILURE: A SYSTEMATIC LITERATURE REVIEW AND  
QUALITATIVE EVIDENCE SYNTHESIS**

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**Word count:** 3637 words

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# BARRIERS AND FACILITATORS FOR CLINICIANS TO ENGAGE WITH ADVANCE CARE PLANNING IN HEART FAILURE: A SYSTEMATIC LITERATURE REVIEW AND QUALITATIVE EVIDENCE SYNTHESIS

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Acknowledgement: Nia Roberts

## ABSTRACT

**Background** Clinicians hesitate to engage with advance care planning (ACP) in heart failure. We aimed to identify the disease specific barriers and facilitators for clinicians to engage with ACP.

**Methods** We searched Medline, Embase, CINAHL, PubMed, Scopus, the British Nursing Index, the Cochrane Library, the EPOC register, ERIC, PsycINFO, the Science Citation Index, and the Grey Literature from inception to July 2018. We conducted the review according to ENTREQ guidelines. Two reviewers independently assessed original and empirical studies according to CASP criteria. The SURE framework and thematic analysis were used to identify barriers and facilitators.

**Results** Of 2308 articles screened, we reviewed the full text of 42 studies. 17 studies were included. The main barriers were lack of disease-specific knowledge about palliative care in heart failure, high emotional impact on clinicians when undertaking ACP, and lack of multidisciplinary collaboration between healthcare professionals in order to reach consensus on when ACP is indicated. The main facilitators were being competent to provide holistic care when using ACP in heart failure, a patient taking the initiative of having an ACP conversation, and having the resources to deliver ACP at a time and place appropriate for the patient.

**Conclusions.** Training healthcare professionals in the delivery of ACP in heart failure might be as important as enabling patients to start an ACP conversation. This two-fold approach may mitigate against the high emotional impact of ACP. Complex interventions are needed to support clinicians as well as patients to engage with ACP.

**Key words:** Heart failure, advance care planning, barriers, facilitators, clinicians, systematic literature review

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BACKGROUND

To be better prepared in the event of a health crisis, conversations about care choices and future care planning in heart failure are widely recommended<sup>1-3</sup>. Advance care planning (ACP) is known to facilitate these conversations<sup>4, 5</sup> and may improve end of life (EOL) care outcomes<sup>6, 7</sup>. But a number of studies have shown that clinicians are hesitant to engage with ACP in clinical practice<sup>8, 9</sup>. Only the minority of eligible patients were given the opportunity of having these conversations<sup>10</sup>. As a result, patient care in heart failure is affected<sup>4</sup>. Only 37% of patients with end-stage heart failure were aware of a poor prognosis, merely 8% of patients and 44% of family members were told by clinicians that time was short, and 36% of these patients died alone<sup>11</sup>. The barriers and facilitators for *clinicians* to engage with ACP in heart failure have not been systematically evaluated.

Commented [MS3]: The reference has been updated from a more recent paper i.e. Adler et al. (2009)

Past reviews looked at barriers to ACP or conversations in heart failure, but no review had rigorously assessed the qualitative evidence base for barriers and facilitators to engage *clinicians* with ACP in heart failure. Lund et al's<sup>12</sup> systematic review investigated the barriers and facilitators to the implementation of ACP focussing on their workability and integration in clinical practice. However, their review did not concentrate on heart failure and addressed only to some extent the barriers facing clinicians. The review by Barclay et al.<sup>13</sup> investigated the literature concerning conversations between professionals and patients suffering from heart failure but did not focus on barriers to ACP. Momen's et al.<sup>14</sup> narrative synthesis reviewed the extent to which there was evidence that conversations with heart failure patients occurred in practice and built on findings from Barclay's work. Similarly, her narrative did not focus on barriers to the implementation of ACP. Slort et al.<sup>15</sup> identified barriers and facilitators for the general practitioner – patient communication in palliative care. While some of their findings were relevant to this study, the authors did not focus on heart failure or on barriers to the implementation of ACP by clinicians. De Vleminck et al.<sup>16</sup> did explore perceived factors hindering or helping GPs in engaging with ACP but a focus on the disease-specific barriers to heart failure was missing. A qualitative synthesis of the evidence by Smeets et al.<sup>17</sup> sought to identify barriers and facilitators for optimal care in heart failure from a GP's perspective. But the study did only concentrate on the clinical management aspects of heart failure rather than on what might improve clinicians' behaviour to initiate ACP. Consequently, a focus on ACP was lacking. Hence, the gap in the evidence was an identification of barriers and facilitators to the engagement of clinicians with ACP in heart failure.

AIM AND OBJECTIVES

The aim of this study was to conduct an exploratory systematic review of qualitative studies investigating the barriers and facilitators to the implementation of ACP by clinicians in heart failure.

The objectives were as follows:

- To identify the barriers and facilitators to the implementation of ACP by healthcare professionals in heart failure
- To synthesise the evidence on recommendations on how to engage clinicians with ACP in heart failure

## METHODS

We conducted the review according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement<sup>18</sup>. This included, but was not limited to, defining the research aims and objectives, developing a review protocol, conducting data base searches, extracting data based on in- and exclusion criteria, assessing the methodological quality of studies and synthesising the evidence<sup>19, 20</sup>.

## Inclusion/ Exclusion Criteria

### Types of studies

We included studies that used qualitative study designs and reported original and empirical study data. Qualitative methods for data collection were focus groups, interviews, observational studies, surveys and document analysis. Studies had to address barriers and facilitators for healthcare professionals to engage with ACP in heart failure. Barriers and facilitators were defined as predisposing factors described by clinicians that either impede or promote their engagement with ACP<sup>21</sup>. Studies describing other terminal illnesses but not heart failure were excluded from the primary analysis. Studies that described ACP for people with life-limiting illnesses that involved heart failure were included. Editorials and narrative reviews were excluded unless they presented original study findings.

### Types of participants

Participants included were all healthcare professionals like GPs, primary care nurses, palliative care consultants and nurses, cardiologists, heart failure specialist nurses, providing EOL care for patients suffering from heart failure. Studies that solely focussed on patients without any reference to healthcare providers were excluded from the review.

### Types of interventions

ACP was defined as a *process* of formal decision-making that aimed at helping patients make decisions about their future care<sup>4</sup>. As such ACP could provide an opportunity for clinicians to clarify a patient's care preferences in anticipation of future loss of mental capacity. This could involve future treatment choices or resuscitation options. In this way, ACP was meant to reduce uncertainty about a course of action should the clinical status of a patient deteriorate and capacity is lost<sup>22</sup>.

**Commented [MS4]:** We have clarified that we have included studies that involved other life-limiting illnesses if they included heart failure. We have discussed this as a limitation in the discussion section which states: "Some studies included other life-limiting illnesses like cancer or COPD in addition to patients suffering from heart failure. Consequently, our findings may have been affected by barriers and facilitators to the implementation of ACP that exist in other end-of-life conditions and not just heart failure."

Types of outcome and healthcare setting

We included studies that primarily described the perceptions and experiences of healthcare professionals on barriers and facilitators to their engagement with ACP in clinical practice. The healthcare setting could be primary care, nursing homes, secondary care, hospital or hospices.

Search strategy and data sources

Studies were retrieved through systematic searches of electronic data bases, screening reference lists and contacting authors. Together with a specialist health science librarian (NR), we searched the following data sources: Medline, Embase, CINAHL, PubMed, Scopus, the British Nursing Index, the Cochrane Library, the EPOC register, ERIC, PsycINFO, Science Citation Index, and the Grey Literature. We searched data bases from their inception until July 2018. An example of a MEDLINE search strategy is provided in **Appendix 1**. Additionally; we searched the reference lists of five reviews<sup>12, 13, 15-17</sup> and all potential relevant cross references and records to identify any other studies. Where required, we contacted the study authors or experts in the field for further information.

Data analysis

We elected to use a thematic synthesis approach which drew on the methods from thematic analysis of primary sources<sup>23</sup> and managed these findings with the SURE framework<sup>24</sup>. The SURE framework (**Appendix 2**) had been validated across a number of healthcare sectors as a systematic yet flexible approach to analysing and categorising qualitative data to inform healthcare policy<sup>25-27</sup>.

Selection of studies

Two reviewers (SC, MS) independently assessed titles and abstracts of identified studies against inclusion criteria. Full text papers were retrieved if the content was potentially relevant to one or both authors. Two authors (MS, SC) evaluated whether these studies should be included in the review. Differences between reviewers were resolved by discussion. A list of excluded papers with reasons for their exclusion is given in **Appendix 3**.

Data extraction and management

Initially, we extracted the background information on each included study (study objectives, study design and methods, participants) and summarized these in tables. Following that, we designed a data extraction sheet that was informed by components of the SURE framework. Components of the data extraction focussed on barriers and facilitators to implementing ACP by clinicians in healthcare systems. We extracted data from included studies and mapped them on to the relevant categories of the SURE framework.



## Quality assessment

Two authors (MS, SC) independently assessed the quality of included studies by using the Critical Appraisal Skills Programme (CASP) quality assessment tool<sup>28</sup>. We used its seven main quality criteria for assessment (**Appendix 4**). Each criterion was assessed with 'yes' or 'no.' If the study did not present adequate information, the rating was 'no.' This resulted in a total quality score ranging from 0 to 7 after applying equal weights. Individual studies were categorised as high quality (ratings from 6 to 7), medium quality (ratings from 4 to 5), and low quality (scores equal or lower than 3). We excluded studies of poor quality and resolved differences by discussion.

## Data synthesis and analysis

Findings were corroborated narratively using a thematic synthesis approach which drew on the methods from thematic analysis of primary sources, extending them to systematic reviews<sup>29</sup>. Thematic synthesis was one of a number of methods suggested by the Cochrane Qualitative Review Methods Group<sup>30</sup> where evidence was likely to be largely descriptive as opposed to highly theorised or conceptual. After reading the text of each study, we developed 'descriptive themes.' We (MS, BW, JIM) discussed the set of descriptive themes which informed the categories of the SURE framework as a pragmatic approach that was designed to inform healthcare policy.

## RESULTS

The literature search identified 2308 potentially eligible studies, of these, 17 papers were included in the final qualitative synthesis (**Figure 1**. PRISMA Flow Diagram). Most studies (n=11) were conducted in the UK. Two studies were undertaken in Australia<sup>31, 32</sup>, one in Canada<sup>33</sup>, one in Sweden<sup>34</sup>, the USA<sup>35</sup> and Belgium<sup>16</sup>. The majority of studies (n=13) included clinicians from primary care. A summary of included study characteristics is given in **Table 1**.

Figure 1. PRISMA flow diagram

**Commented [MS5]:** We have used the original PRISMA diagram (see Figure 1) and have updated our results.

Study ID	Country	Relevant study objectives:	Study Design	Participants	CASP Quality assessment (Score)
Barnes (2006) <sup>36</sup>	UK	To explore attitudes of primary care professionals and older people toward communication of diagnosis, prognosis and symptoms in CHF	Focus groups with HCPs and interviews with patients	39 GPs, 37 nurses, 2 health visitors, 1 nursing home manager, 41 patients with CHF	High (6)
Bloomer (2013) <sup>31</sup>	Australia	To explore and identify the preparedness and ability of nurses to provide end of life care through the patient's dying phase and their families	Focus groups study with clinical nursing and management staff	12 nurses from an intensive care unit looking after cardiac and surgical patients	High (6)
Boyd (2004) <sup>37</sup>	UK	To identify some barriers and facilitators for clinicians to engage in ACP with patients in their last phase of life.	Interviews and focus groups with patients, carers and clinicians	16 clinicians from primary and secondary care, social and palliative care specialists	High (7)
Brooks (2017) <sup>32</sup>	Australia	To explore the experiences of physicians and nurses on barriers and enablers to providing EOL care	Focus group study	11 physicians and 17 nurses at an intensive care unit	High (6)
Close (2013) <sup>38</sup>	UK	To examine the experience of heart failure diagnosis of HCPs, nursing home staff and residents	Qualitative interviews	5 GPs, 3 HF nurses, 17 nursing home residents	High (6)
De Vleminck (2014) <sup>16</sup>	Belgium	To identify barriers from a GPs perspective to initiating ACP and to gain insight into any differences in barriers between cancer, CHF and dementia	Five focus groups with General Practitioners	36 General Practitioners looking after terminally ill patients	High (6)
Denvir (2014) <sup>39</sup>	UK	To explore the optimal content and design of a trial on EOL intervention for advanced heart disease	Community and hospital based focus groups and interviews	11 Primary and secondary care healthcare professionals	High (6)
Fuat (2003) <sup>40</sup>	UK	To ascertain the beliefs and decision-making practices of GPs in the heart failure	Focus group study	30 GPs	Medium (5)
Glogowska (2015) <sup>41</sup>	UK	To explore perceptions and experiences of HCPs caring for patients suffering from HF	Qualitative interview study	24 HCPs including GPs, cardiologists, geriatricians, HF specialist nurses	High (7)
Hancock (2014) <sup>42</sup>	UK	To explore changes in HCPs views about the diagnosis and management of HF	Focus groups and a national survey	56 focus group participants (39 GPs, 4 cardiologists, 6 general physician, 7 HF nurses); 514 survey responses	High (7)
Hanratty (2002) <sup>43</sup>	UK	To identify doctors' perceptions of the need for palliative care for heart failure and barriers to change	Focus groups study	34 GPs, cardiologists, geriatricians, medical and palliative care doctors	High (6)

<b>Hayes (2015)<sup>33</sup></b>	Canada	To identify the potential challenges and opportunities to improve care for CHF in the community	Clinician interview series	28 HCPs including 5 GPs, 8 cardiologists, 8 nurses, and 4 pharmacists, 3 admin staff	High (7)
<b>Hjelmfors (2014)<sup>34</sup></b>	Sweden	To describe nurses' perspective on discussing EOL issues and prognosis with CHF patients	National survey	111 heart failure nurses	High (6)
<b>Murray (2015)<sup>44</sup></b>	UK	To document the barriers and facilitators to palliative care in the community	European survey	Primary care HCPs from 20 European nations	High (7)
<b>Ostertag (2008)<sup>35</sup></b>	USA	To identify concerns about EOLC amongst HCPs and members of the community	Interview and focus group study	14 primary care physicians, 19 hospice staff, 18 nursing home staff, 19 carers	Medium (5)
<b>Selman (2007)<sup>45</sup></b>	UK	To investigate communication between staff, patients and carers on EOL issues for patients suffering from heart failure	Semi-structured qualitative interviews	20 patients with CHF, 11 carers, 6 palliative care clinicians and 6 cardiology clinicians	High (7)
<b>Seymour (2010)<sup>46</sup></b>	UK	To identify factors surrounding community nurses' implementation of ACP and nurses educational needs	Six focus group discussions and three workshops	23 community nurses looking after patients affected by a terminal illness	High (7)
<b>Abbreviations</b>	<b>CHF:</b> congestive heart failure; <b>EOL:</b> end of life; <b>EOLC:</b> end of life care; <b>GP:</b> General Practitioner; <b>HCP:</b> healthcare professional; <b>HF:</b> heart failure;				

Table 1. Characteristics of included studies

Methodological quality of studies

Of the 17 papers, we rated 15 as high quality (CASP score 6-7) and two as medium quality (CASP score 4-5)<sup>35, 40</sup>. One study was excluded due to low quality<sup>47</sup>. The CASP quality ratings of the included studies are summarized in **Table 2**.

Study ID	CASP question addressed:						
	Yes = +	No = o					
	1	2	3	4	5	6	7
Barnes (2006)	+	+	+	+	+	o	+
Bloomer (2013)	+	+	+	+	+	+	o
Boyd (2004)	+	+	+	+	+	+	+
Brooks (2017)	+	+	+	+	+	o	+
Close (2013)	+	+	+	+	+	o	+
De Vleminck (2014)	+	+	+	+	+	+	o
Denvir (2014)	+	+	+	+	+	o	+
Fuat (2003)	+	+	+	+	o	+	o
Glogowska (2015)	+	+	+	+	+	+	+
Hancock (2014)	+	+	+	+	+	+	+
Hanratty (2002)	+	+	+	+	+	+	o
Hayes (2015)	+	+	+	+	+	+	+
Hjelmfors (2014)	+	+	+	+	o	+	+
Murray (2015)	+	+	+	+	+	+	+
Ostertag (2008)	+	+	+	+	o	o	+
Selman (2007)	+	+	+	+	+	+	+
Seymour (2010)	+	+	+	+	+	o	+

Table 2. CASP quality assessment

Barriers and facilitators

We summarised the factors reported as barriers and facilitators for the engagement of clinicians with ACP in heart failure using the SURE framework (**Table 3**). All barriers and facilitators at a clinician level were categorised under a) knowledge and skills, b) attitudes regarding ACP’s acceptability, appropriateness and credibility, and c) motivation to engage with ACP.

Factors affecting implementation of ACP	Barriers	Facilitators
Knowledge and skills	<ul style="list-style-type: none"> <li>lack of knowledge about palliative care in heart failure (e.g. the complexity of drugs, ICDs, CRTs)<sup>16, 31, 36, 37, 40, 42, 44, 45</sup></li> <li>lack of knowledge about the legal differences between ACP and ADRTs<sup>16, 35, 44, 46</sup></li> <li>uncertainty about HF prognosis<sup>34, 39, 42, 43, 45</sup></li> <li>lack of EOL communication and negotiations skills<sup>16, 34, 45</sup></li> <li>lack of time to start and complete an ACP conversation<sup>16, 31, 34, 39, 41</sup></li> <li>lack of collaboration with other HCPs about the patient<sup>32, 40</sup></li> <li>not remembering to initiate ACP in the rush of everyday clinical practice<sup>16, 31</sup></li> <li>using euphemisms when talking about heart failure and the prognosis<sup>32, 42, 46</sup></li> </ul>	<ul style="list-style-type: none"> <li>being competent about palliative care in heart failure<sup>36, 37, 42, 45</sup></li> <li>knowing what ACP is and what it is not<sup>16, 44, 46</sup></li> <li>knowing the legal differences between ACP, ADRTs or living wills<sup>16, 35, 46</sup></li> <li>creating more time by having ACP conversations in the context of a home visit or by booking double appointments<sup>32, 34, 42, 46</sup></li> <li>being able to engage patients in shared decision-making and ACP<sup>32, 37, 40, 42</sup></li> <li>consultation with other HCPs about next steps in EOLC for the patient<sup>35, 40</sup></li> <li>having some sort of reminder to indicate the need to do ACP for a patient<sup>16, 46</sup></li> <li>being able to clarify what a patient wants to know and what a patient does not want to know<sup>36, 45</sup></li> </ul>
Attitudes regarding ACP's acceptability, appropriateness and credibility	<ul style="list-style-type: none"> <li>uncertainty about timing of ACP<sup>16, 34, 45, 46</sup></li> <li>emotional difficulties of having an ACP conversation<sup>16, 42, 45</sup></li> <li>ACP perceived as admitting defeat or as a failure to a medical treatment prerogative<sup>32, 39</sup></li> <li>believing that cardiologists or heart failure specialist nurses are better suited than GPs because of their expertise<sup>16, 38, 41-43</sup></li> <li>believing that GPs are better suited than cardiologists because they have a long-standing relationship with the patient<sup>16, 41</sup></li> <li>waiting for the patient to start a conversation about EOL issues<sup>16, 36, 37</sup></li> <li>concerns about the impact of ACP on the patient and the family<sup>36, 41</sup></li> </ul>	<ul style="list-style-type: none"> <li>knowing the patient and family to identify the appropriate moment to have an EOL conversation<sup>16, 31</sup></li> <li>knowing a patient's care preferences and values<sup>34, 36</sup></li> <li>being able to provide a range of treatment options appropriate to the patient's phase of illness<sup>16, 45</sup></li> <li>sharing information between primary- and secondary healthcare teams to identify who is the appropriate HCP to have an ACP conversation and when<sup>16, 32, 33, 37-41, 43</sup></li> <li>empowering patients to initiate EOL conversations with their healthcare provider<sup>16, 36, 41</sup></li> </ul>
Motivation to engage with ACP	<ul style="list-style-type: none"> <li>not wanting to alarm patients<sup>16, 36, 46</sup></li> <li>not wanting to destroy hope when initiating ACP conversations<sup>34, 39, 46</sup></li> <li>being afraid of talking about death and dying<sup>32, 36, 41, 46</sup></li> <li>fear of damaging the clinician - patient relationship<sup>46</sup></li> <li>fear of suggesting to patients that HCPs give up<sup>38</sup> on them when introducing ACP<sup>39</sup></li> <li>lack of human resources discourages HCPs to undertake ACP<sup>31, 42, 46</sup></li> </ul>	<ul style="list-style-type: none"> <li>being able to provide holistic end of life care<sup>33, 36, 37, 39</sup></li> <li>knowing that patients want their HCPs to be honest with them<sup>32, 36, 41</sup></li> <li>being able to improve the quality of life for patients and their carers when doing ACP<sup>38, 46</sup></li> <li>an opportunity to be open and transparent with patients and give them a chance to prepare for the end of life<sup>32, 46</sup></li> <li>increased resources in terms of time and staff to undertake ACP and provide 'good' EOLC<sup>31, 42</sup></li> </ul>
<b>Abbreviations:</b> ACP: advance care planning; ADRTs: advance decisions to refuse treatment; CRT: Cardiac Resynchronization Therapy; EOL: end of life; EOLC: end of life care; HCPs: healthcare professionals; HF: heart failure; ICD: implantable cardioverter defibrillator;		

Table 3. Barriers and facilitators for clinicians to engage with ACP

**Barriers to clinicians**

We identified the following key barriers to the engagement of clinicians with ACP in heart failure:

- **Knowledge and skills**

One common reported barrier for clinicians to engage with ACP in heart failure was a lack of heart failure disease-specific knowledge<sup>36, 40, 44, 45</sup> which mainly affected GPs<sup>42</sup>, primary care nurses or palliative care staff<sup>33</sup>. This related predominantly to the complexity of available drugs or the use of implantable cardioverter defibrillator (ICDs) and cardiac resynchronization therapy (CRT)<sup>37, 33, 42</sup>. Many times, this disease-specific barrier was aggravated by uncertainty about the prognosis of the illness which prevented ACP from taking place<sup>34, 36</sup>.

Furthermore, healthcare professionals described a lack of knowledge about ACP in general<sup>33, 46</sup>, what ACP should contain or what the legal differences were between ACP and advance decisions to refuse treatment (ADRTs)<sup>35, 46</sup>. This in turn made communication about ACP very challenging for clinicians. A number of studies described a lack of communication- and negotiation skills in EOLC as a barrier to the implementation of ACP<sup>32, 46, 48</sup>. Euphemisms were seen as a way to avoid talking about heart failure as a diagnosis<sup>42</sup> as well as the terminal nature of the disease<sup>16, 36</sup>. However, the use of euphemisms was generally not endorsed by healthcare staff<sup>32</sup>.

- **Attitudes regarding ACP’s acceptability, appropriateness and credibility**

One attitude emerging as a barrier in implementing ACP by clinicians in heart failure was the perception that in doing so a healthcare professional would admit defeat and treatment failure<sup>34</sup>. This was associated with a considerable negative, emotional impact<sup>45</sup>. Similarly, some studies reported that clinicians saw engaging with ACP as a setback to any curative treatment effort<sup>42, 49</sup>. This attitude applied more to cardiologists than to primary or palliative care staff<sup>40</sup>. Another barrier for not undertaking ACP was a lack of collaboration between healthcare professionals. Cardiologists believed that a GP was better suited to have an ACP conversation due to a GP’s long-standing relationship with the patient<sup>43</sup>. Conversely, some GPs thought that the cardiologist was the professional with the content expertise and therefore should start ACP<sup>38</sup>. There was a general lack of communication between the medical disciplines on the issue<sup>37, 42</sup>. Others reported that clinicians waited for the patient to initiate these discussions so that they were sure it was the appropriate time to engage with ACP<sup>46</sup>. Underlying that lack of initiative were also fears and concerns of not wanting to upset the patient or the family<sup>34, 38</sup>.

- **Motivation to engage with ACP**

Not wanting to cause alarm to patients or carers was a key motivational barrier for clinicians not to engage with ACP<sup>34</sup>. They feared that in delivering ACP, healthcare professionals would destroy hope<sup>37</sup>. Another study reported that their own fear of talking about death and dying was another reason for not speaking to patients about the last phase of life<sup>33</sup>. Some clinicians feared that starting an ACP discussion would

indicate to a patient that they would give up on them and consequently damage their doctor-patient relationship<sup>46, 49</sup>. Another major factor that discouraged clinicians from engaging with ACP was a lack of resources<sup>37, 38, 40, 44, 46</sup>, mainly time, qualified staff<sup>38</sup> and the right opportunity to address such a sensitive topic<sup>39</sup>. Additional barriers to motivation of healthcare professionals to carry out ACP were the competing demands of their clinical role. Workloads and stress often prevented some clinicians from undertaking ACP in heart failure<sup>37, 42</sup>.

## Facilitators for clinicians

Studies reported a number of significant facilitators to engage clinicians with ACP in heart failure:

- **Knowledge and skills**

Being competent in managing the complexities of palliative care in heart failure was a key factor for clinicians to engage with ACP<sup>36, 46</sup>. Other studies reported that a robust knowledge of drug regimens and the issues surrounding the use of ICDs and CRTs boosted a clinician's confidence to start the ACP process<sup>41, 45</sup>. Healthcare professionals were also more likely to deliver ACP if they had a good understanding about what were the essential criteria of ACP<sup>36, 44, 46</sup>. This was especially relevant when understanding the legal differences between ACP, ADRTs or living wills<sup>46</sup>.

Essential skills for implementing ACP were reported as being able to identify the level of a patient's need for information<sup>36</sup>, clarifying a patient's care preferences and values<sup>31</sup> or being able to engage a patient in a shared decision-making process on all available treatment options<sup>32, 37</sup>. Study participants described that obtaining or maintaining these skills always involved some form of training<sup>37, 43, 48</sup>. These skills were also relevant when introducing the topic of ACP to a patient<sup>36, 44, 46</sup>. Starting the ACP process could happen in the context of an outpatient appointment, a routine medication review or after a hospital admission when the patient was in a stable medical condition<sup>42</sup>.

- **Attitudes regarding ACP's acceptability, appropriateness and credibility**

Studies reported a number of attitudes that appeared to promote clinicians' engagement with ACP. Some thought that ACP was easier to initiate when they knew the patient and family well<sup>32</sup>. The context of a long-term doctor - patient relationship was conducive for a clinician to identify the right place and time to have an EOL conversation<sup>34, 41</sup>. Similarly, the timing for an ACP conversation was seen as appropriate when a patient initiated the conversation<sup>41</sup>. Some clinicians described a sense of relief when this occurred<sup>46</sup>. Additionally, starting the ACP process was perceived as being easier when primary- and secondary healthcare teams collaborated well and had reached consensus on a patient<sup>33, 37, 41, 44</sup>.

- **Motivation to engage with ACP**

One of the key motivations for clinicians to deliver ACP was being able to provide good or holistic<sup>37</sup> EOL care. Some clinicians thought that ACP was able to improve the quality of life for patients and their carers<sup>35, 37</sup>. ACP gave clinicians the stimulus to be open and transparent<sup>35</sup> and created an opportunity to prepare patients for their



last phase of their life<sup>43</sup>. A few studies described that an increase in human resources including more staff time and finances were additional motivational factors to deliver ACP<sup>37, 42, 44</sup>. To resolve the lack of time, some healthcare professionals started ACP in the context of a home visit<sup>37</sup> or by booking a double clinic appointment. Others arranged follow-up visits after the initial conversation to address any unresolved issues<sup>38, 46</sup>.

DISCUSSION

This review synthesised the qualitative evidence from 17 primary studies on barriers and facilitators to the engagement of clinicians with ACP in heart failure. Systematic review methods were based on recommended standards to enhance transparency and reporting for qualitative evidence<sup>19</sup>.

Significant themes for barriers to the engagement of clinicians with ACP in heart failure were:

- Lack of disease-specific knowledge about palliative care in heart failure
- Lack of skills in communicating ACP with a patient suffering from heart failure
- Lack of collaboration between healthcare professionals in order to reach consensus on when ACP is indicated
- The high emotional impact on the healthcare professional when undertaking ACP

Important themes for facilitators to help clinicians engage with ACP in heart failure were:

- Being competent in the use of ACP and the clinical management of end stage heart failure
- Being able to provide holistic EOL care when using ACP
- Having a trusting and long-term relationship with the patient and carers
- A patient initiating an ACP conversation
- Being able to deliver ACP at a time and place appropriate for the patient

Comparison with existing literature

Several of our findings on barriers and facilitators concurred with those from other reviews: the complexity and inherent uncertainty of some aspects of end-stage heart failure management<sup>17</sup>, skills in initiating ACP and communicating EOL issues<sup>13, 49</sup> or having sufficient resources<sup>12</sup> and a functioning network of collaborations between medical specialities<sup>17</sup> applied to our results as well. Educating and training clinicians in the delivery of ACP should help them become more skilled with the process of initiating these conversations. Being able to conduct these discussions was seen as important, since there were suggestions that supportive or palliative care for heart failure patients should be made available at all stages of the disease trajectory<sup>50</sup>. Having these conversations as a normal part of heart failure management was balanced by the precaution to adjust the dialogue to a patient’s need for information in order to avoid a loss of hope or an increase in anxiety<sup>14</sup>. This applied particularly to patients who did not want to talk about EOL issues or engage with ACP<sup>51</sup>. Again,

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this precaution had to be considered in the context that a number of clinicians avoided disclosing the diagnosis of heart failure all together or evaded answering any questions about the prognosis of the illness<sup>52</sup>. But the majority of patients preferred open and honest information about their condition while maintaining a sense of hope<sup>51</sup>. So, the training of clinicians in communicating ACP sensitively seemed even more important.

### Strengths and limitations

This was the first qualitative synthesis specifically addressing barriers and facilitators for engaging clinicians with ACP in heart failure. Several of our findings concurred with other reviews. However, the global transferability of our qualitative results may be limited since the majority of included studies were based in the UK. Some studies included other life-limiting illnesses like cancer or COPD in addition to patients suffering from heart failure. Some studies included other life-limiting illnesses like cancer or COPD in addition to patients suffering from heart failure. Consequently, our findings may have been affected by barriers and facilitators to the implementation of ACP that exist in other end-of-life conditions and not just heart failure.

The SURE framework proved to be helpful in facilitating an understanding of the barriers and facilitators to the implementation of ACP in the published literature. This approach facilitated the synthesise of findings from the thematic analysis in a systematic way according to healthcare professionals' knowledge and skills, their attitudes regarding ACP's acceptability, appropriateness and credibility and their motivation to engage with ACP. Once we achieved consensus on the barriers and facilitators in included papers, mapping these to the SURE structure was efficient and straight forward.

Conversely, using the SURE framework largely centred the analysis of thematic findings on barriers and facilitators to the implementation of ACP by clinicians. This approach may have limited the diversity of qualitative data and narrowed the complexity of the phenomenon under investigation to factors affecting the implementation of the intervention by clinicians. Consequently, there may have been a risk that other themes outside the scope of SURE were not sufficiently considered like the wider political or cultural context of ACP.

A novel finding from this review suggests that patients may hold the key in engaging clinicians with ACP<sup>41</sup>. Their initiative in starting an ACP conversation might have the potential to mitigate against the high emotional impact on healthcare professionals<sup>33, 38</sup>. The literature suggests that, for example, question prompt lists (QPLs) have the potential to empower patients to initiate EOL conversations with their healthcare provider<sup>53</sup>. If a patient initiates the discussion about ACP in heart failure, clinicians may feel less reticent about raising the topic by responding to a patient's question. A number of studies report a small but significant increase in questions by patients about diagnosis, prognosis and treatment when a QPL had been used<sup>53, 54</sup>. Most of these studies investigated the effect of QPLs in a cancer setting. Further research for the effect of QPLs on patients suffering from heart failure is still outstanding since these studies investigated the effect of QPLs in a cancer setting.

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**Conclusions and recommendations**

This review has shown that clinicians often lack disease-specific knowledge about the clinical management of advanced heart failure and the confidence to engage with EOL issues and ACP. Available evidence suggests that training clinicians should include skills to identify the level of a patient’s need for information, clarifying a patient’s care preferences and values and being able to engage a patient in a conversation on all available treatment options. There are a number of suggested methods to achieve these skills which may include interactive educational meetings involving role play preferably facilitated by local opinion leaders and experts in the field of heart failure to enhance clinicians’ engagement.

Based on current findings, training clinicians in the delivery of ACP in heart failure might be equally important to assisting patients to start an ACP conversation. This two-fold approach may mitigate against the high emotional impact of ACP on healthcare professionals. Complex interventions are needed to support both, clinicians as well as patients, to engage with ACP in heart failure.

Commented [MS9]: All references have been deleted from the conclusion and recommendation section.

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## DECLARATIONS

### Contributorship

The list of authors including the main author, Markus Schichtel (MS), and the co-authors, Bee Wee (BW), John I. MacArtney (JIM), and Sarah Collins (SC) represents all those who can legitimately claim authorship by making a substantial contribution. MS had the idea for the review, wrote the protocol, extracted, evaluated and analysed the data, wrote, critically revised and submitted the entire manuscript. BW critically supervised the conduct of the review and revised the entire manuscript. JIM critically revised the study protocol, the narrative synthesis as well as the SURE analysis of barriers and facilitators. SC independently screened papers, extracted data and evaluated the study quality according to the CASP assessment tool. All co-authors approved the version to be published.

### Funding

This research and authors received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### Competing interests

The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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### Ethics statement

This systematic review and narrative synthesis did not require ethics approval.

### Acknowledgements

We thank Nia Roberts, health science librarian, Bodleian Library, University of Oxford, for running the literature data base searches.



PRISMA 2009 Flow Diagram

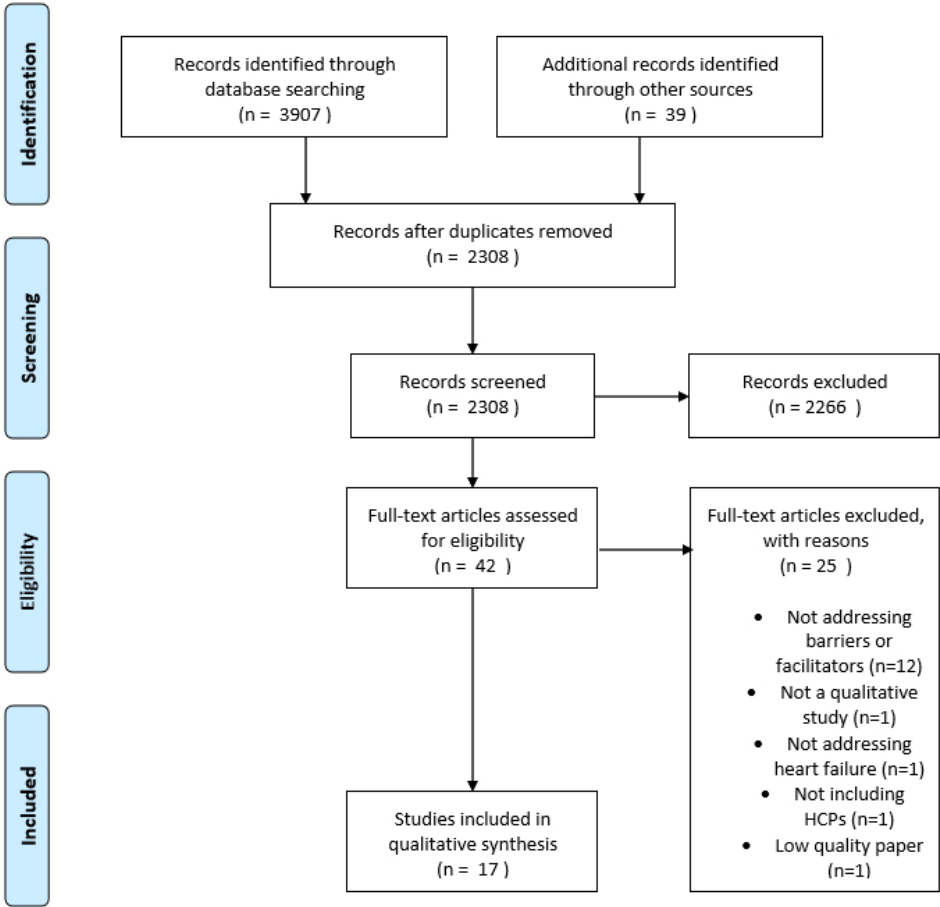


Figure 1 PRISMA Flow-diagram

190x210mm (96 x 96 DPI)

Appendix 1. Medline Search	Results
exp Heart Failure/	107923
Heart assist devices/ or Defibrillators, Implantable/	26004
((heart or cardiac) adj2 failure).ti,ab.	154116
((left ventric* or right ventric* or biventric*) adj2 failure).ti,ab.	6666
(hf or ahf or chf).ti,ab.	50746
((heart or ventric*) adj2 assist device?).ti,ab.	9681
(implant* adj2 (defibrillator? or cardiover*)).ti,ab.	13290
1 or 2 or 3 or 4 or 5 or 6 or 7	234634
exp Advance Care Planning/	8297
palliative care/ or exp terminal care/	86989
Terminally Ill/	6154
(advance* adj2 (care plan* or directive* or statement*)).ti,ab.	5497
living will*.ti,ab.	1172
"do not resuscitate".ti,ab.	1880
"right to die".ti,ab.	903
(resuscitation adj3 (plan* or order* or wish*)).ti,ab.	458
((write or written or writing or make? or made or making) adj3 will?).ti,ab.	11747
((write or written or writing or make? or made or making) adj3 care plan*).ti,ab.	343
("end of life" adj3 (plan* or care)).ti,ab.	9586
("end of life" adj3 place*).ti,ab.	76
("end of life" adj3 (rite? or wish or wishes)).ti,ab.	199
("end of life" adj3 (home? or hospital? or hospice?)).ti,ab.	701
(palliative care or palliative therap* or palliative treat*).ti,ab.	30553
(terminal care or terminal therap* or terminal treat* or terminal* ill*).ti,ab.	7953
((death or dying) adj3 plan*).ti,ab.	1413
((death or dying or die?) adj3 place*).ti,ab.	3471
((death or dying or final) adj2 (rite? or wish or wishes)).ti,ab.	229
((death or dying or die?) adj3 (home? or hospital? or hospice?)).ti,ab.	16862
euthanasia.ti,ab.	9834
(assisted adj2 (death or dying or suicide)).ti,ab.	3558
"Tissue and Organ Procurement"/	16159
(organ adj3 (donor* or donation)).ti,ab.	11332
9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32	165744
(barrier* or challenge* or constraint? or hinder* or hindrance or obstacl* or disempower* or discourag* or inequit* or inequalit*).ti,ab.	951263
(facilitat* or opportunit* or empower* or enab* or encourag* or equit* or equalit*).ti,ab.	1121477
(implement* or adopt* or transfer* or translat* or integrat* or cooperat* or co-operat* or coordinat* or co-ordinat* or collaborat* or tailor*).ti,ab.	2171378
34 or 35 or 36	3696141
8 and 33 and 37	867

Appendix 2. Excluded studies

Study ID	Reason for exclusion
Allen 2012	Low focus on review question; not a qualitative study; paper is an executive summary on decision-making in advanced heart failure
Boyd 2009	Low quality CASP score of study and focus on review question
Denvir 2015	Low focus on review question; not a qualitative study; paper describes future care planning and staged implementation of ACP, anticipatory care planning in heart failure; low focus on barriers and facilitators to the implementation of ACP by healthcare professionals
Detering 2014	Lack of focus on review question; paper describes the evaluation of a brief multimodality education programme
Gibbs 2002	Not a qualitative study; paper describes the role palliative care for patients living and dying from heart failure
Gibbs 2006	Survey of specialist palliative care services for heart failure; paper has a low focus on review objective;
Haga 2012	Low focus on the study objective: paper describes an observational cohort of 138 community based patients but does not focus on HCPs barriers and facilitators to the implementation of ACP
Hanratty 2006	Low focus on study objective: does not go into detail on barriers and facilitators of ACP in heart failure
Jaarsma 2009	Descriptive paper but not a qualitative study; paper is a position statement from the heart failure association of the European Society of Cardiology
Johnson 2006	Not a qualitative study and low focus on study objective; paper describes issues with palliative care service provision for heart failure
Johnson 2007	Not a qualitative study; paper describes management of end-stage heart failure; lack of focus on research objective
Kavalieratos 2014	Lack of focus on review objectives; aim of the paper is to characterize unresolved symptom and treatment needs with which heart failure patients present
Knauft 2005	Lack of focus on heart failure: paper looks at patients suffering from COPD
LeMond 2011	Not a qualitative study; paper describes palliative management for heart failure
LeMond 2015	Lack of focus on review question: paper describes concept on shared decision-making but does not address in detail barriers and facilitators to ACP
McIlvennan 2016	Lack of focus on review question: focus of the paper is to describe palliative care for heart failure more from a clinical management point of view
Murray 2002	Low of focus on review questions: did not address barriers and facilitators to ACP for HCPs
Murray 2004	Lack of focus on review question: did not address barriers and facilitators to ACP for HCPs
Simon 2015	Paper focusses exclusively on patients, does not include the perspectives of HCPs on barriers and facilitators to the implementation of ACP in heart failure

## Appendix 3. SURE Framework

Level	Factors affecting implementation
<i>Recipients of care</i>	Knowledge and skills
	Attitudes regarding programme acceptability, appropriateness and credibility
	Motivation to change or adopt new behavior
<i>Providers of care</i>	Knowledge and skills
	Attitudes regarding programme acceptability, appropriateness and credibility
	Motivation to change or adopt new behavior
<i>Other stakeholders (including other healthcare providers, community health committees, community leaders, programme managers, donors, policymakers and opinion leaders)</i>	Knowledge and skills
	Attitudes regarding programme acceptability, appropriateness and credibility
	Motivation to change or adopt new behavior
<i>Health system constraints</i>	Accessibility of care
	Financial resources
	Human resources
	Educational and training system, including recruitment and selection
	Clinical supervision, support structures and guidelines
	Internal communication
	External communication
	Allocation of authority
	Accountability
	Community participation
	Management and/or leadership
	Information systems
	Scale of private sector care
	Facilities
	Patient flow processes
	Procurement and distribution systems
<i>Social and political constraints</i>	Incentives
	Bureaucracy
	Relationship with norms and standards
	Ideology
	Governance
	Short-term thinking
	Contracts
	Legislation or regulation
	Donor policies
	Influential people
	Corruption
	Political stability and commitment



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3 **Appendix 4. CASP Questions**  
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6  
7 **1. Was there a clear statement of the aims of the research?** ☐ Yes ☐ Can't tell ☐ No

8 HINT: Consider ☐ What was the goal of the research? ☐ Why it was thought important? ☐ Its relevance  
9

10 **2. Is a qualitative methodology appropriate?** ☐ Yes ☐ Can't tell ☐ No

11 HINT: Consider ☐ If the research seeks to interpret or illuminate the actions and/or subjective experiences of  
12 research participants ☐ Is qualitative research the right methodology for addressing the research goal?  
13

14 Is it worth continuing?  
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18 **3. Was the research design appropriate to address the aims of the research?**

19 ☐ Yes ☐ Can't tell ☐ No  
20

21 HINT: Consider ☐ If the researcher has justified the research design (e.g. have they discussed how they decided  
22 which method to use)?  
23

24 **4. Was the recruitment strategy appropriate to the aims of the research?** ☐ Yes ☐ Can't tell ☐ No  
25

26 HINT: Consider ☐ If the researcher has explained how the participants were selected ☐ If they explained why  
27 the participants they selected were the most appropriate to provide access to the type of knowledge sought by  
28 the study ☐ If there are any discussions around recruitment (e.g. why some people chose not to take part)  
29

30 **5. Was the data collected in a way that addressed research issue?**  
31

32 ☐ Yes ☐ Can't tell ☐ No the  
33

34 HINT: Consider ☐ If the setting for data collection was justified ☐ If it is clear how data were collected (e.g.  
35 focus group, semi-structured interview etc.) ☐ If the researcher has justified the methods chosen ☐ If the  
36 researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews  
37 were conducted, or did they use a topic guide)?  
38

39 **6. Has the relationship between researcher and participants been adequately considered?**

40 ☐ Yes ☐ Can't tell ☐ No  
41

42 HINT: Consider ☐ If the researcher critically examined their own role, potential bias and influence during (a)  
43 Formulation of the research questions (b) Data collection, including sample recruitment and choice of location  
44 ☐ How the researcher responded to events during the study and whether they considered the implications of any  
45 changes in the research design .  
46

47 **7. Have ethical issues been taken into consideration?** ☐ Yes ☐ Can't tell ☐ No

48 HINT: Consider ☐ If there are sufficient details of how the research was explained to participants for the reader  
49 to assess whether ethical standards were maintained ☐ If the researcher has discussed issues raised by the study  
50 (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the  
51 participants during and after the study) ☐ If approval has been sought from the ethics committee  
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Required amendments for paper BMJspacare-2018-001747	Amendments were addressed by
<p>1. Embedded Figures</p> <ul style="list-style-type: none"> <li>• Please remove all figures from the body of the manuscript and re-upload your figure files separately.</li> <li>• Please note that we do not accept figures in Word document, PowerPoint or PDF format.</li> <li>• All figures and images should be supplied as high quality image files, we recommend PNG, TIFF or JPG/JPEG. Please ensure images are a minimum of 300dpi and a maximum of 600dpi (resolution).</li> </ul>	<ul style="list-style-type: none"> <li>• All figures are removed from the body of the manuscript and uploaded separately</li> <li>• The PRISMA flow-diagram is uploaded as a figure in TIFF format.</li> </ul>
<p>2. Title page</p> <ul style="list-style-type: none"> <li>• Kindly make sure that the title page should be embedded at the first page of your main document</li> <li>• Make sure the word count does not exceed the limit and is provided on the title page</li> </ul>	<p>The title page is now embedded as the first page of the main document.</p> <p>The main manuscript contains the abstract The word count is within limits and on the title page.</p>
<p>3. Supplementary file / Appendix Please be informed that this should be in PDF Format.</p>	<p>The supplementary file is now in PDF format.</p>
<p>4. Word Count Please make sure that the word count is provided on the title page. Be sure that it does not exceed the requested count.</p>	<p>The word count is provided on the title page.</p>
<p>5. Include the following statements in the main document: contributorship, funding, competing interests, exclusive license, ethics statement</p>	<p>These statements are now part of the main document.</p>
<p>6. Include a marked copy</p>	<p>A marked copy has been included.</p>
<p>Reviewer 1/ Associate Editor Comments</p>	
<p>Update your search</p>	<p>We had updated the original literature (March 2018) review with result from a search in July 2018. We have now formally evaluated these new results. We did not find any additional relevant papers. The PRISMA flow diagram, and search results have been updated accordingly.</p>
<p>Please choose MeSH terms for your keywords</p>	<p>We have included heart failure, advance care planning, barriers, facilitators, clinicians as keywords</p>
<p>Methods: How would have dealt with a paper that described ACP for people heart failure and other life-limiting illnesses?</p>	<p>Studies that described ACP for people with other life-limiting illnesses that involved heart failure were included in the review. The limitation of this 'mixed' study populations is now acknowledged under limitations in the discussion section and states:</p> <p>"Some studies included other life-limiting illnesses like cancer or COPD in addition to patients suffering from heart failure. Consequently, our findings may have been affected by barriers and facilitators to the implementation of ACP that exist in other end-of-life conditions and not just heart failure."</p>
<p>Use the original PRISMA diagram and update your results</p>	<p>We have used the original PRISMA diagram and updated our results.</p>
<p>Reviewer 2</p>	
<p>You reference a paper by McCarthy, Hall and Ley which was published in 1997. The figures cited add shock value - only 8% of heart failure patients were told time was short but there must be more recent papers than this.</p>	<p>We have updated the reference with a more recent paper from Eric D. Adler , Judith Z. Goldfinger , Jill Kalman , Michelle E. Park , and Diane E. Meier et al. (2009). "Palliative Care in the Treatment of Advanced Heart Failure. <a href="https://doi.org/10.1161/CIRCULATIONAHA.109.869123">https://doi.org/10.1161/CIRCULATIONAHA.109.869123</a> Circulation. 2009;120:2597–2606</p>
<p>the discussion section - This repeats the findings in bullet point but there is little discussion and interpretation of their</p>	<p>The first paragraph of the discussion section (i.e. the bullet points) are meant to summarise the principal</p>

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<p>significance. This should be addressed before this paper can be published.</p>	<p>findings of the literature review. While this may seem like a repetition of content, it is standard practice of starting the discussion section of a systematic review.</p> <p>We have made an effort to constructively interpret the significance of the findings in relation to the other literature. The sub-sections “Comparison with existing literature” in the Discussion part which compares our findings with that of other reviews.</p> <p>The last paragraph in the following subsection “Strengths and Limitations” now highlights the novelty of the main findings from this review compares this with existing literature.</p> <p>All references have been deleted from the conclusion and recommendation section.</p>
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